

# Hawai'i State Council on Developmental Disabilities 2006 ANNUAL REPORT



## Mission Statement

The mission of the Council is to support people with developmental disabilities to control their own destiny and determine the quality of life they live.

## Vision Statement

People with disabilities are treated equally and enjoy fundamental human rights, among them life, liberty and the pursuit of happiness. They have choices about where they live, work and play, and they receive the supports they need to do so.

## Implementation Statement

To this end, the Council will:

- ⊗ work for self-determination;
- ⊗ advocate for systems change;
- ⊗ provide information, education and planning;
- ⊗ serve as conscience/monitor of the State; and
- ⊗ promote best practices.

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## FROM THE CHAIR...

*Aloha!*

*As your DD Council Chair, it has been my privilege to preside over another year of growth and service at the Council.*

*We've continued our longstanding activities, such as the 12<sup>th</sup> Partners in Policymaking academy and the annual Day at the Capitol, and added new ones, including a Community Inclusion strand at the Pacific Rim Conference on Disabilities as well as a Students with Intellectual Disabilities and Postsecondary Education Capacity Building Institute preceding PacRim.*

*We were successful in initiating and advocating for groundbreaking legislation for persons with developmental disabilities to exercise individual choice in determining their own residential setting.*

*To highlight just a few accomplishments: the Public Awareness, Self-Determination and Training Committee completed the production of a "Storytellers" DVD which is targeted at educating high school students about disability while emphasizing how much young people with disabilities have in common with their "typical" peers. The Community Supports Committee published a handbook to help individuals with disabilities and their families understand and better utilize the Medicaid Home and Community-Based Services waiver.*

*With extensive public input, the Council developed a new state plan to guide its efforts during the next five years.*

*Mahalo,*



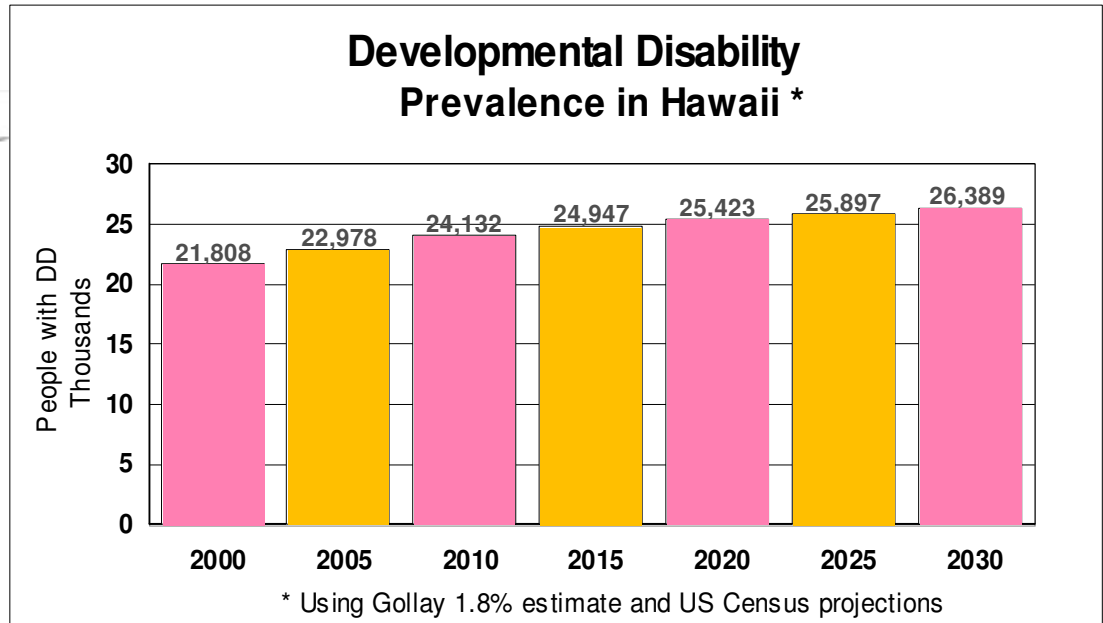
*Mark F. Romoser  
Chair*

## COUNCIL MEMBERSHIP...

Maggie Baxter	Jean Kiyabu
Joan Bellard	Elvira Lee
William Burwell	Makia Malo
Oralie Carter	Evan Murakami
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Naomi Grossman	John Noland
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Dr. Patricia Heu	Mark Romoser
Paul Higa	Michael Tada
Liz Ann Ihu	Charlene Tarr
Dr. Jean Johnson	J. Curtis Tyler III
Charlotte Kamauoha	Paul Vargas
Bernadette Keliiaa	Betsy Whitney



*The Partners in Policymaking 12th Academy participants pose at the Pagoda Hotel.*



## THE COUNCIL...

State Councils were established in response to the federal *Developmental Disabilities Services and Facilities Construction Act of 1970* (PL 91-517). Hawai‘i’s Council was established in State Law by Act 198, Session Laws of Hawai‘i in 1975.

The Council is administratively attached to the Department of Health (DOH). The department serves as the designated state agency, providing fiduciary and administrative support.

The Council engages in activities which change the system of services for people with developmental disabilities and conducts systems change, capacity building, and advocacy activities that...

- ✿ Provide training for individuals with developmental disabilities and their families including legislative advocacy, training on the legislative process, and leadership development
- ✿ Demonstrate new approaches to services, supports, and assistance
- ✿ Inform federal, state, and local policymakers
- ✿ Foster interagency collaboration and coordination
- ✿ Eliminate barriers and enhancing the design and redesign of systems
- ✿ Maintain a resource library with articles, books, research studies, and videos that may be borrowed free of charge
- ✿ Develop and support coalitions
- ✿ Educate the public
- ✿ Coordinate and support community activities that follow the Council’s mission

The Council, appointed by the Governor, is a group of individuals dedicated to improving the lives of Hawai‘i’s citizens with developmental disabilities. The philosophy of membership is that all key stakeholders are represented at the Council table: individuals with developmental disabilities; their family members, advocates; representatives of state and private agencies who provide services; representatives of the Hawai‘i Disability Rights Center (HDRC), the state’s Protection and Advocacy agency; University of Hawai‘i’s Center on Disability Studies (CDS) and other key community interests. The beauty of this composition is in the skills and experience that each brings to the table and shares with other Council members.

*Legislators representing Maui get together with their constituents during Day at the Capitol*

## DEVELOPMENTAL DISABILITY

[from PL 106-402, Sec. 102. Definitions, (8)]

(A) IN GENERAL.—The term “developmental disability” means a severe, chronic disability of an individual that—

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN.—

An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.



## MAJOR ISSUES IN DEVELOPMENTAL DISABILITIES...

In August 2005, the state Medicaid agency unveiled a plan to move the ABD population into managed care. Currently, the ABD population is served by a fee-for service program which has not been very effective in delivering health care services especially in rural area where providers and specialists are scarce. The Council has provided ongoing input through participation on an advisory committee and at public forums. Council efforts insured the inclusion of self-advocates in the process. The current plan is to fold in the ABD population in July 2008.

The DD/MR waiver renewal application has been approved by the Centers for Medicaid and Medicare Services effective July 1, 2006. Supports/services available under the renewal waiver include: Adult Day Health, Assistive Technology, Chore, DD/MR Emergency Services – Outreach, Respite, and Shelter, Environmental Accessibility Adaptations, Personal Assistance/Habilitation, Personal Emergency Response System, Residential Habilitation, Respite, Skilled Nursing, Specialized Medical Equipment and Supplies, Supported Employment, Transportation, Training and Consultation, and Vehicle Modifications. Consumer-directed services have been expanded to include Respite in addition to Personal Assistance/Habilitation and Chore services.

The Waiver Policy Advisory Committee (PAC) has been involved in the development of the service definitions and standards for the renewal waiver application. CMS approved the application effective July 2006. A focus of the Waiver PAC has also been on training for agencies and direct support workers, the development of an individual budgeting process, the development of guidelines for personal assistance services provided for children, and quality assurance.

The Council advocated for and supported legislation to address two of the Residential Settings Task Force's recommendations, and both pieces of legislation were enacted into State law by

the 2006 Legislature. The first, Act 261 (SB 2630 SD2 HD1 CD1) addressed the appropriation of funds to provide for continued operation of Developmental Disabilities (DD) Domiciliary homes and DD apartment complexes thereby maintaining current residential options for those individuals. The second, Act 303 (HB 2098 HD1 SD1 CD1) enables an individual to make the choice of residential settings, provided that the person can be sustained with supports and adequate consideration is given to the person's safety and well-being.

The Council actively monitored, tracked and supported measures related to autism, dental care, disability access, disaster preparedness, early intervention, education, emergency appropriations for DD and early intervention services, family caregivers, individual choice of residential setting, language access, long-term care, Medicaid and Medicare services, reproductive rights protection, residential services, and transportation.

The Council continued its support of the implementation of Act 133/1998 incorporating the principles of self-determination into state law. The challenge associated with implementing self-determination is the person-centered planning process which must reflect a person's choices, preferences, and strengths while balancing the state budget. As the state moves toward consumer-directed services, more options in residential settings and housing options will continue to be explored and other funding opportunities pursued.

The Quality Assurance Subcommittee formed by the DD Division has been meeting to discuss quality issues regarding waiver services. The subcommittee identified the following issues/topics as priority for discussion: identifying clear outcomes for individuals to guide service delivery, consumer guide for families and individuals, and qualifications of direct support workers.

## Employment

The Council participated on the Advisory Council for the Medicaid Infrastructure Grant (Hire Abilities Hawaii). The two-year \$1 million planning grant awarded to the UH Center on Disability Studies aims to increase employment options for individuals with mental illness and developmental disabilities. The first year of the grant focused on an analysis of barriers and solutions through data gathering and focus groups. The grant is in its second year of implementation and is focusing on the development of Medicaid Buy-In program; benefits planning; and the use of personal assistance services for individuals with disabilities to obtain and sustain employment.

The Council obtained preliminary data on employment outcomes of individuals with developmental disabilities from the Division of Vocational Rehabilitation (DVR). The Council also obtained data on consumer awareness and utilization of

work incentive programs through the Medicaid Infrastructure Grant. The Council plans to continue to work with DVR and other agencies to obtain additional employment data.

In 2005, the Council sponsored a Capacity Building Institute (CBI) focusing on post-secondary education options such as vocational or technical school training, adult education, and college, which could enhance employment outcomes for individuals with developmental disabilities. The CBI generated interest in this area, and in 2006 the DOE agreed to fund a one-year pilot (Ka Imi Na'auao: Support in Seeking Knowledge Project) focusing on creating access to post-secondary education for students to increase their career options and choices and prepare them for employment. The Council collaborated with the DOE on the one-year project that focuses on the Leeward Area School Complex.





## Quality Assurance



*Note: The term “quality assurance” is defined broadly in DD Council’s enabling statute, PL 106-402, to include “advocacy, capacity building, and systemic change activities;” “self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians;” and “activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities.”*

Efforts to implement the state’s Olmstead Plan were re-initiated via an interagency implementation task force in March 2006 with the Council participating and insisting on self-advocate involvement. The original plan had been completed and sent to the governor’s office for approval in November 2002. The Council played an important role in collaboration with other advocacy groups in keeping the Olmstead planning process alive.

Partners in Policymaking completed its 12th academy in January 2006 with 18 new graduates. 195 self-advocates and family members have completed the program to date. Partners’ graduates continue to serve the community through leadership roles on boards, committees and coalitions.

The Council-sponsored Day at the Capitol was held in March. More than 350 participants representing all counties had the opportunity to meet with legislators and their staff to share their personal stories and express concerns about

available DD services and issues such as dental care, disability access, employment, family support, waiver services, residential services, funding for DD and early intervention services, housing, and respite. They met with legislators, attended House and Senate floor sessions, and had an opportunity to tour the Capitol and network with others.

The Council completed production of a public awareness Storyteller Project. The DVD which will be introduced to teachers through classes in the College of Education features six storytellers with disabilities talking about experiences during their teen and young adult years with the purpose of promoting disability awareness to high school students. The stories focus on the issues of inclusion and diversity. The DVD was previewed at the 2006 PacRim conference and received extremely positive feedback. The Council also co-sponsored a Community Inclusion strand at the conference.



## Health



In September 2005, the Council developed and published the first version of guidebook for the Home and Community Based Services for persons with developmental disabilities or mental retardation Medicaid Waiver. The Council distributed over 200 guidebooks to individuals, families, and professionals through various agencies as part of a statewide pilot project aimed at evaluating the effectiveness of the guidebook. In January 2006, the pilot was completed and the results of a written survey were compiled. The Council received positive feedback and requests for a wider distribution of the guidebook. Comments and suggestions for change were also gathered and the Council plans to update the guidebook consistent with the implementation of the new Medicaid Waiver.

Dental care services continue to be a priority issue for the disability community. The Council supported the state Medicaid agency in obtaining funds from the legislature passed to provide preventive and restorative dental services to adults on Medicaid and QUEST. In connection with those services, a new effort is planned to recruit more dentists as Medicaid providers. Finding a provider for those individuals who require anesthesia for dental procedures continues to be difficult. A Council-supported

legislative measure which appropriated \$90,000 to look at improving dental services to persons with disabilities was passed by the state legislature. It mentions using “federally qualified health centers,” allowing greater flexibility in treatment, and training among other issues. The Council in collaboration with the National Foundation on Dentistry for the Handicapped was able to extend the Donated Dental Services Program for an additional year. Access to children’s dental services although covered under EPSDT has not been well-utilized especially in rural areas.

The Council continues to monitor the results from the National Core Indicators which provide an insight into the quality of services being received by individuals with developmental disabilities. The Council participated in adding additional questions about health status to the survey relating to access to medical and dental services.

As the lead for health services for medically fragile children in the schools shifts from the Health to Education, the Council has been looking at what needs to happen for a smooth transition. Costs to support the children in a school setting have greatly increased in the last few years. There is also a lack of service providers.



## Education



The Council monitored and tracked the federal regulations proposed for the Individuals with Disabilities Education Improvement Act of 2004 (IDEA Reauthorization). The Council was part of a workgroup that was established to address inconsistencies, if any, between the proposed federal regulations and the State administrative rules of the Department of Education (DOE). The workgroup completed its analysis and recommendations for amendments. The IDEA 2004 final regulations were published in the Federal Register in August 2006.

During the 2006 Legislative session, legislation was introduced that attempted to clarify concerns about which party has the burden of proof in appealing administrative hearings brought under IDEA. The Council supported legislation placing the burden of proof on the DOE. Although no legislation was passed, the Council continues to work with advocacy agencies regarding this concern.

The Council has participated on the Advisory Council for the Family Support 360 Project (Kokua I Holomua) since January 2005. The project is part of a three-year grant that aims to assist students with developmental disabilities

transitioning from high school to adulthood and their families in Windward Oahu with locating appropriate and available services and supports in the community. The grant focuses on collaboration between partner agencies toward the creation of a navigational one-stop system where navigators assist students and families with identifying needed supports and in determining and reaching their goals. The grant is in its second year of implementation and has provided essential training for families, created navigators who have assisted families to successfully navigate the complex service and support systems in the community, and is nearing completion of the development of competencies for the navigational one-stop system.

In March 2006, the Council sponsored and organized a breakout panel session at the Pacific Rim Conference entitled “Looking at Successful High School Transitions.” The focus of the session was on education and model transition programs or services for students with developmental disabilities. Two high school teachers/transition coordinators and the Director of a Youth One-Stop Center presented on their transition programs and what they have done to make them successful.



## Housing



The 2005 State Legislature adopted HCR 40 HD 1 – Requesting the Hawaii State Council to Continue to Convene the Residential Settings Task Force to Identify Issues and Solutions Regarding Individuals with Developmental Disabilities and Their Choice of Residential Setting. This resolution provided the basis for the Council to reconvene the Task Force. The Task Force continued its work and submitted a follow-up report (Phase 2) to the 2006 Legislature. The report described residential options currently available for individuals with developmental disabilities, addressed individual choice and self-determination in increasing residential options, identified statutes, administrative rules, policies, and directives that if revised would allow settings that do not require licensure and reflect individual choice, assure civil rights, health and safety. The report also outlined the details of additional recommendations.

The Council advocated for and supported legislation to address two of the Task Force’s recommendations, and both pieces of legislation were enacted into State law by the 2006 Legislature. The first, Act 261 (SB 2630 SD2 HD1 CD1) addressed the appropriation of funds to provide for continued operation of Developmental Disabilities (DD) Domiciliary homes and apartment complexes thereby maintaining current residential options for those individuals. The second, Act 303 (HB 2098 HD1 SD1 CD1) enables an individual to have the choice of residential setting, provided that the person can be sustained with supports and adequate consideration is given to the person’s safety and well-being.

The Council successfully inserted an amendment to a housing bill which resulted in adding a “person with a disability or advocate for people with disabilities” to the membership of the Public Housing Authority.



*Senator Chun Oakland (left) and Speaker Say (right) talk story with Day at the Capitol participants.*

# HIGHLIGHTED ACTIVITIES

## Neighbor Island Activities

### Kaua'i

The Kauai DD Committee sponsored community forums bringing individuals with developmental disabilities as well as family members and State and County officials. The forum focused on available resources and services to individuals with disabilities, access to recreation, school to community transition, dental services, income received by individuals who live below income levels, supported employment, housing and legislation. The members also attended a "Day at the Capitol" event in which they were able to meet with legislators, tour the Capitol, meet the Governor, and attend hearings throughout the day. Members also worked with the Mayor's Committee on emergency preparedness, as well as the county Parks and Recreation Committee to increase accessibility and accommodations in the area of recreation. Members also were involved with the Children's Council of Kauai working on areas of education and equal access for all children of Kauai in schools and school based activities.

### Maui

The Maui Disability Alliance, a coalition of 16 different disability provider agencies and support groups, held its 10<sup>th</sup> Annual Legislative Forum in October 2005. The focus of the forum was small groups working to examine and address issues facing individuals with disabilities. Each group recorded what success they've had and what barriers they faced. The Mayor, members of the County Council, and state legislators participated. The Maui County budget for public transportation tripled. As a result of the increase, there will be Sunday service, longer hours and increased frequency on all existing routes. The committee supported an amendment the County Charter to use 2% of the Real Property Tax to create an affordable housing fund, and participated in the Maui Nui Affordable Housing Task Force. A tri-isle planning retreat sponsored by the Community Children's Councils of Hana, Lana'i, Moloka'i and Maui identified and explored educational issues in these communities.

### Hawai'i

This year, members of the East and West Hawaii DD Committees collaborated with the County of Hawaii to implement Project Lifesaver. Both Committees have prioritized the need to improve oral health services, and they continue their advocacy work addressing the many oral health care concerns that effect people with developmental disabilities. The East and West Hawaii DD Committees have advocated strongly for the proposed implementation of hospital dentistry services. The East and West Hawaii DD Committees hosted and co-sponsored two legislative forums and variety of meetings and trainings on resources available for the community on topics including, dental care, Medicaid, transportation, missing persons, Community Personal Assistance and Supports (CPASS), Wright's Law, self-esteem and sexuality, and abuse.

## Partners in Policymaking

Eighteen individuals from across the state completed the 12th Partners training in 2006. Presently, there are 195 Hawai'i *Partners* graduates. Many graduates are serving the community in leadership roles on councils, commissions, and coalitions and as service providers and as self-advocates. The planning has already started for the Partners Thirteenth Session. Partners are selected from all geographic areas across the State.

*Partners in Policymaking* is an innovative program for individuals with developmental disabilities and their family members. The program is designed to provide information, training, resources and skills, to develop productive partnerships between people who need and use services and those in a position to make policy and law. It teaches people to be community leaders and educates participants about current issues and best practices in the disabilities field, and informs them about the policymaking and legislative process.

## Legislative Update

The Council actively monitored, tracked and supported measures related to autism, dental care, disability access, disaster preparedness, early intervention, education, emergency appropriations for DD and early intervention services, family caregivers, individual choice of residential setting, language access, long-term care, Medicaid and Medicare services, reproductive rights protection, residential services, and transportation.

### *In Memory of Katherine Higa*

*Katherine Higa, the DD Council account clerk for more than 33 years passed away on August 30, 2005. We miss her amazing ability to deal with numbers on a daily basis but most of all we miss her smile, her laugh, and her positive attitude toward life.*



## HOW WE CAN BE REACHED...

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#### From the Neighbor Islands:

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## COUNCIL STAFF...

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Howard Marks,  
Program Specialist, Big Island  
Susan Kawano,  
Secretary  
Rachel Gonzales,  
Clerk Typist

## Acronyms

ABD	Aged, Blind, and Disabled
CBI	Capacity Building Institute
CD	Conference Draft
CDS	Center on Disability Studies (University of Hawai'i)
CMS	Centers for Medicare & Medicaid Services
CPASS	Community Personal Assistance Services & Supports
DD	Developmental Disabilities
DD/MR	Developmental Disabilities/Mental Retardation
DOE	Department of Education
DOH	Department of Health
DVD	Digital Video Disc
EPSDT	Early & Periodic Screening, Diagnosis, & Treatment
HB	House Bill
HCR	House Concurrent Resolution
HD	House Draft
HDRC	Hawai'i Disability Rights Center
IDEA	Individuals with Disabilities Education Act
PAC	Policy Advisory Committee
PL	Public Law
SB	Senate Bill
SD	Senate Draft
UH	University of Hawai'i